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Review

# The UK Biobank project: Trust and altruism are alive and well
# A model for achieving public support for research using personal data

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"*Reciprocity leads to social cohesion.*"
"Robert M.L. Winston. Human Instinct."

## 1. Introduction

The paper by Andrew Trehearne[1] about the UK Biobank in this issue of the International Journal of Surgery is to be welcomed. It is important that everybody learns more about this project: most people are aware of it thanks to the fact that it has been widely promoted to both the general public and health professionals. When the UK Biobank opened its doors in Liverpool in January 2009, about 2 years after its launch in April 2007 in Manchester, (already at about the halfway mark in recruiting its target of half a million participants) the excitement of the moment was caught by it being described as a project that would, as it matured, become "an unparalleled treasure chest of vital information on a range of diseases including cancer, heart disease, diabetes, stroke, dementia, depression, arthritis, osteoporosis, skin and lung disorders and many other life-threatening and debilitating conditions."[2] It leads one to wonder what the factors were that contributed to achieving this very rapid recruitment rate. Perhaps we can learn from this model?

## 2. Good communication: the key to effective collaboration

When Biobank is fully mature it will provide a major resource for health scientists seeking to improve our knowledge, understanding and handling of many diseases. But, as Dr. Tim Sprousen, the UK Biobank Chief Scientist identified, it has already yielded one of its most important findings that should be noted by anyone undertaking collaborative research – research **with** people rather than **on** people. This is the finding he mentioned: that when people feel properly informed they will respond in the positive. He also said: "People support research, and will do so in great numbers if they have the right information to hand." Therein lies the key – taking care to provide 'the right information' in a timely fashion. Scrutiny of Biobank's methods described in Trehearne's editorial, and elaborated elsewhere, shows that this did not happen by chance. By way of a random example of the care that was taken, in June 2005 the UK Biobank Ethics and Governance Council[3] were giving careful consideration to the suitability of the patient information leaflet at the time of the pilot progress report:

"*The Patient Information Leaflet (PIL) will be evaluated according to these three aspects of the participant's experience*:

- *What did the participant think of the invitation letter*?
- *What was the participants' (sic) expectation of the assessment centre visit*?
- *Was there any aspect of the assessment visit that the participant had not anticipated and/or had been surprised by*?"

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This level of consideration for prospective participants, iterating with them, demonstrated that by careful communication and thorough planning by a multi-talented team, using well thought-out and imaginative strategies, ensured that when the letter of invitation dropped through the letterbox of a prospective participant, the recipient would have a good idea what the project was about, and that their GP and practice manager would too. It is reported that the UK Biobank Information Centre at Cardiff University has been well used, mostly by people wanting to know more about the project. Any piece of research, no matter whether large or small, whether it is a randomized controlled trial, a survey or a public consultation seeking respondents, will produce better quality information, more rapid accrual and more useful data if careful planning and preparation is undertaken to achieve good understanding and co-operation. This exploration should include thorough consideration of the manner of approach to potential participants. This may in some instances require pre-research qualitative studies which may, amongst other things, help to determine participants' information needs (or even health professionals' information needs[4]) as well as their attitude to the acceptability of the study being proposed[5] – and the manner in which it is being offered. Imposed research is doomed to failure: "the people's health is the concern of the people themselves".[6] Feasibility or pilot studies (such as undertaken for Biobank in Altrincham, Cheshire, in 2007, the year before launch) can help to reveal any shortcomings or flaws that need remedying before a project becomes fully operational. Today, there is a range of research methods to draw on to suit the particular requirements and objectives of a proposal.[7]

## 3. Trust, confidence and altruism

As described by Trehearne, from the moment participation starts with the receipt of the letter of invitation to attend for a 90-min assessment visit, potential participants are treated with consideration, courtesy and respect. Although participants are provided with a list of their measurements at the end of the visit, and some attempt at putting them into context, they know they will receive no feedback at any stage – it is not a health-check. This means that members of the public have given their time, their data, their samples, knowing that they are contributing to an enterprise that aims to improve the human lot rather than be of benefit individually. But that is not all that they have given: they have placed their trust in the people responsible for UK Biobank's work and exhibited confidence in the processes and systems put in place to secure their safety and protection. They are aware that signing up to this communal effort will not bring benefit to them personally, but evidently feel it is worth doing because it will be of benefit to numerous others in the future. Not just their own kith and kin, but unknown strangers anywhere. They might be surprised to know that they have contributed to 'prospective epidemiology'!

That altruism is alive and well in a technological, materialistic age is a cause for rejoicing. It gives witness to a high level of trust: trusting members of the public giving their personal data, trusting those collecting the data to handle it securely and safely so that it might be used for the common good in decades to come. This trust presupposes confidence in the processes and systems that have been set up to obtain, handle and store data and samples, and to ensure that these data will be properly drawn on and used for the purposes for which they were obtained. But those setting up this giant databank had in the first place to trust that ordinary members of the public would come forward to reciprocate that trust. Their trust was earned, not blindly given.

## 4. Vision

Those who had the vision to plan and set up UK Biobank will have drawn hope and inspiration from two fruitful long-term prospective epidemiological studies that Trehearne mentions: Sir Richard Doll's project to find out what caused lung cancer[8] and the Framingham Heart Study.[9] It is instructive for us to look back at this work that Sir Richard began with Sir Austin Bradford Hill in 1948[10] in order to remind ourselves of those early days of epidemiology; what took place, the slow pace of change, the general reluctance to accept findings or take action about smoking. It is pleasing to think that Sir Richard lived long enough to witness the outcome of his vision to accomplish this meticulous, ground-breaking work. It also provides a salutary lesson: that objectivity and patience are required by those who aspire to producing reliable data resources.

The Framingham Heart study, also begun in 1948, was "an ambitious project in health research to identify the common factors that contribute to cardiovascular disease". Development of the disease was followed over a long period of time in a large group of participants. Of particular interest is the Study Bibliography which shows a bar chart of 'Articles Published per Decade Based on Framingham Data' over the last 6 decades: a total of 1973 articles, increasing in number through all six decades, from 15 in 1950–1959 rising steadily through to 785 in 2000–2008.

## 5. Conclusion

It is difficult to avoid superlatives when considering the potential of the Biobank 'treasure chest' to make an impact on health care when it is fully filled, particularly remembering the means we have at our disposal today for safe storage, retrieval and use of data. This time of data-gathering is ideal for promoting optimism. Just as Sir Richard Doll and Sir Austin Bradford Hill's work and the Framingham Heart Study have provided inspirational models for worthwhile long-term endeavours, this project should serve as a model to demonstrate just what is necessary to tap into the enthusiasm of people to make them glad and willing to donate personal data and samples in order to be part of a worthwhile research undertaking for the good of humanity. At the very least we see that the science of medical research is dependent upon the art (and science) of good communication practiced by those who value and respect the dignity of every involved individual.

*Conflict of interest*

The author has no conflict of interest.

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